“Jonas’ Cookery School”

Our road to independence - a child with CHARGE syndrome learns to cook

Jonas was born in May 2004 with CHARGE syndrome. He has everything there is to have with CHARGE syndrome. Colobomas - so-called fissures - in both eyes, severe sensorineural hearing loss in both ears, a defective vestibular system, extremely low muscle tone, swallowing difficulties and respiratory problems, to name just a few. Due to the severity of his visual and hearing impairments, Jonas qualifies as a deaf-blind / hearing-impaired person.

Visually, Jonas is able to orientate himself competently in familiar and well-known environments. To be able to see well at school, he needs a screen magnifier and enlarged worksheets. In terms of hearing ability, he has been fitted with hearing aids but, in addition to the spoken language, he occasionally needs sign language or visual materials to support a better understanding.

Jonas is currently in Year 6 of a lower secondary school and has a dedicated learning assistant to help him in class.

His life plan is to get rid of the tracheotomy at 16, to have a beard at 17, to drive a car at 18, and to live alone at 20. With the exception of driving, most things are certainly feasible, even if we may still have to juggle a little with the timescale.

For the last three years Jonas has been regularly supervised by a paediatric psychologist. She has often advised us to give him tasks and allow him to take responsibility for certain things. As Jonas often lacks strength, balance and/or visual orientation, it is not always easy to find him something to do. But small tasks work reasonably well. These can be changing towels, or emptying his rubbish bin every day (if the rubbish bin is too full, he cannot carry it and loses everything on the way - hence the idea of doing it on a daily basis). “Living alone” at the age of 20, however, is in a different league to simply taking the rubbish out.

A great opportunity for Jonas to learn something new suddenly arose during the summer holidays when his two sisters (aged 8 and 5) spent 1½ weeks at their grandparents’ home in Berlin. This was the perfect time to concentrate fully on Jonas, giving him the peace and quiet that he always needs in order to try new things. I had no concrete plan about what I wanted to do but I did know that it should be a practical life-skill. And because of his interest in the daily food plan (it is important for Jonas to be able to check that there is something on the menu that he really can eat and likes), I decided on cookery.

Here is a small insight into our “cookery school”, which took place over a total of 17 days. I have not described every single day, but selected the most significant stages and moments. We took lots of photos because Jonas kept saying: “Take a picture and send it to Daddy and Grandma!”
Day 1 – Potatoes with curd cheese

Jonas doesn't know yet how lucky he is, but around noon I ask him if he would like to help me cook something in the kitchen. Extremely enthusiastic, he doesn't hesitate at all and comes into the kitchen straight away.

Jonas: “Would you like me to cook something?”
I: “Yes, today we’re going to practice cooking.”
Jonas: “And why’s that?”
I: “Don’t you want to live alone when you're 20?”
Jonas: “Yes, when I’m 20, I’m going to have the house to myself.”
I: “Yes, and then you have to be able to cook, otherwise you can't live alone.”
Jonas: “Okay. And what do I have to do now?”

I had decided we would start with potatoes with curd cheese (“Quark”). I took on the task of preparing the potatoes and Jonas was supposed to make the curd cheese. Actually, all he had to do was open two tubs of curd cheese, put it all into a bowl, stir in some milk, and season to taste. Pulling the lid off the curd cheese was the first obstacle. With a little help and Mummy’s strength, it worked out quite well. As it is not easy getting all the cheese out, he also needed practice in scraping a tub empty. Jonas has no sense of smell and, therefore, also a distorted sense of taste so I did the seasoning. Stirring the cheese curd posed another small challenge because you need a hand-whisk, which he had not come across before. You also need strength to stir, and you have to use both hands - one hand to hold the bowl and one hand to stir.

Day 2 – One practice is not enough...

Fully motivated, we embark on the second day of our cookery school. Even so, we had to begin by clarifying why Jonas should join in again.

Jonas: “Are we going to cook again?”
I: “Yes, today we're going to cook something together again.”
Jonas: “But I can already cook.”
I: “Cooking only once is not enough. To be able to cook, you have to practice every day.”
Jonas: “But I have been practicing.”
I: “Yes, yesterday we practiced and today we’re going to practice some more. And tomorrow, too, and the day after tomorrow. You need a lot of practice if you want to be
able to live alone.”
Jonas: “Okay, let’s practice again.”

Today, we are cooking mashed potatoes with an hollandaise sauce and hard-boiled eggs. After realising that you can’t cook several dishes at the same time, Jonas decided to make the sauce and I made the mashed potatoes. His first task was to find a cooking pot. But where are our pots? And what exactly is a pot? We looked for them together and, with my help, we chose the right size. Jonas put the kettle on to boil the water and, at the same time, which was almost too complicated a step, we peeled the eggs and used an egg slicer to cut them. But how do you put an egg into the egg slicer? And what happens to the sliced egg afterwards?

In the meantime, the water was already boiling. We then needed a measuring cup, which was something else he was not familiar with. So, we looked for one together. How much water do we need for two 250ml sauce packets? This called for some mental arithmetic. Working it out in one’s head was just too tricky so we had to find a piece of paper and jot the maths down. We quickly figured out that we needed 500ml of water. First we looked for “500” on the scale of the measuring cup, but unfortunately there are several scales printed on the jug (not just liquids), and then we discovered that the printing on the measuring cup was far too small to read. I realised that this measuring cup was definitely not designed for the visually impaired. Even though he measured out the water very well, Jonas still needed someone to reassure him so that he did not feel stressed. Pouring the water into the pot also went well. But please, always use both hands! Stir in the sauce – with Mummy’s help – and, once this is done, add the eggs.

Altogether, this was far too complex for the second day. My patience was really put to the test. I had to find some recipes that are more simple and do not require several things being done at the same time.

I also quickly realised that he hardly knows what the objects in the kitchen are called or what they are used for. But we were happy and enjoyed our lunch that he even served himself onto his plate. This is a first.
Day 3 – The packet soup

I have done a lot of thinking overnight and, with a bit of research on the Internet, have found some simple dishes to cook. Today we will have packet soup. It certainly isn’t the healthiest choice, but one that could be feasible for Jonas.

Jonas: “Are we going to cook again today?”
I: “Yes, we’re cooking again.”
Jonas: “Should I practice again?”
I: “Yes, we’ll practice every day.”
Jonas: “That’s right, every day. And then I can live alone.”
I: “Yes, then one day you can certainly live alone.”

Jonas immediately found a pot, the measuring cup and also an egg-whisk. Wow, what a success! Together, we read the preparation instructions on the packet soup. Almost immediately I noticed that (1) everything is printed far too small and (2) definitely not in simple language. For example, we stumbled over the words “packet contents”. What are “packet contents”? Nevertheless, he worked out how much water he needed and turned on the kettle by himself. Measuring the water also worked well. As he is very interested in numbers and technical devices, he managed to switch on the stove without any problems. However, cutting the packet soup open presented him with a new challenge. He is not yet able to guestimate where to cut the packet open and cut it too close to the top edge. Things that come quite naturally to us, I realised, are not at all self-evident to him.

I explained how to stir the soup into the pot. One hand stirs whilst the other pours the contents into the pot. He did it well and only a small amount spilled. Then recipe said the soup should boil for 8 minutes. Jonas set the timer by himself and disappeared into his room.

I: “Jonas, where are you going?”
Jonas: “I’m going to play.”
I: “But we’re making soup.”
Jonas: “But I have to wait eight minutes anyway.”
I: “Yes, that’s right. But you have to stir the soup and make sure it doesn’t overboil.”
Jonas: “Right, okay, then I’ll carry on.”
I: “And you can set the table.”
Jonas: “But why?”
I: “How are you going to eat the soup?”
Jonas: “Right, okay, I'll set the table.”

We are not just practicing cooking, but also setting the table and finding the right plates. For soup, you use a soup plate and not a flat plate. You take a big spoon, not a small one. Jonas, however, set his place with an ice cream spoon. He is right - it is bigger than the little spoon, but not a soup spoon. There are so many things you need to know!

Just before our soup was ready, I decided that it would be nice to add an egg to the soup. I showed him how to break the egg. Bravely, he tried it himself, but found that it is not as easy as it looks and that quite a lot of slimy glibber comes out of the egg.

**Day 4 – Semolina pudding from the packet**

What works with a packet soup should also work with a packet of semolina pudding, I thought.
Without a lot of talking, we reflected about what we would need today. A pot, an egg-whisk, some milk and a measuring cup. Together, we read through the preparation instructions again and discussed what “briskly boiling” and “… serve with fruit to taste” meant.

I was really forced to wonder if such packets really are simpler to prepare if you don't understand what you are supposed to do because of the way it is formulated. Our challenge today was not letting the milk catch and burn. Quite a difficult stage for Jonas to recognise, and then react to quickly enough. Maybe semolina pudding wasn’t such a good idea, after all? Or can we find another way to boil the milk? I think I shall have to try out a few other possibilities myself in order to work out what is feasible for him and what is not.

Cutting the bag open works better than yesterday because he remembered not to cut it too high. The rest was almost routine. I helped him stir in the semolina because he does not have the strength to whisk everything firmly.

**Day 5 – We need equipment for the disabled**

My plan for today is to make two dishes at once. Mashed potatoes and scrambled eggs.

*Jonas: “Shall I help again?”*  
*I: “Yes, we're going to cook together again.”*  
*Jonas: “For Daddy, too?”*  
*I: “Yes, Daddy will get something after he’s slept in.” (Dad worked the night shift.)*  
*Jonas: “He’s bound to be happy and will definitely be proud.”*  
*I: “Yes, I think so, too.”*

We started with the eggs. I guided his hands for him and we cracked the first eggs together. It turns out that breaking eggs is really difficult when you have limited fine motor skills. Either the egg doesn’t break or it breaks so badly that we end up with a slush of egg and eggshell. Before frying the eggs, I fished some of the egg shell out of the bowl. I did the
seasoning again. He added some milk and mixed it all together. He's doing the best he can. Then Jonas was given the task of getting the frying pan. He handed me a pot. I explained to him that this was a pot but that we needed a frying pan. He looked through all the cupboards, but he did not know what a frying pan looked like. We found one together and got started. After fetching the butter, he put some of it into the pan. I have to keep reminding him to work with both hands. After the butter had melted, he poured the eggs into the pan. I held my breath and hoped that he would not spill too much of it. But he managed. He also noticed for the first time that cooking can be hot. I explained to him that you have to be careful, but nothing will happen if you always hold on to everything properly, or in other words, if you work with both hands! The eggs were almost done, so we turned to the mashed potatoes. Here, too, we used the ready-made type and did not mash the potatoes ourselves. He warmed the water in the kettle in a flash. Today, it was more difficult for him to measure the water and milk, as he could hardly make out the measurements on the cup. Still, we were really doing quite well. Daddy helped to stir in the mashed potatoes at the end, as Jonas had run out of strength.

Today’s insight? We definitely need different kitchen utensils for him. Finding a measuring cup with clearer, larger markings should be easy, but how do people with disabilities break eggs? I asked these questions on Facebook and promptly received some tips for utensils that might help. I was also recommended some cookbooks for the disabled, which we will certainly buy.

Day 6 – Back to square one

Today is not a good day. No matter what we teach and practice with Jonas, there are days when everything just goes back to square one. I know these days happen, and today was unfortunately one of those days.

Everything that had gone so smoothly just didn’t work anymore. We had to start from scratch and learn the names for pot, frying pan, egg-whisk and measuring cup. We had planned on making mashed potatoes and fish fingers, but Jonas was not able to do even the simplest of tasks. For example, when I asked him to get the butter, he
went to the fridge and brought me milk. I asked him if that was butter. He said “No”, and went back to the fridge. He put the milk back and brought me the sliced bread ... And so the whole cookery session continued. In the end, he was able to take on a couple of tasks and I did the rest.

The big issues for both of us today were “patience” and “perseverance”. We knew that tomorrow everything would be fine again and yet we were both disappointed and frustrated.

**Day 7 – Highly motivated, with notes**

*I:* “Jonas, would you like to cook with me again today?”
*Jonas:* “Yeah, sure.”
*I:* “Shall we make some notes with pictures so you know what the utensils in the kitchen are called?”
*Jonas:* “Oh, yes!”
*I:* “Would you like to do it with me on the computer?”
*Jonas:* “Oh, yes, can I write, too?”

I don’t know why I had not come up with this idea much earlier. But when we have days like yesterday, I am reminded how much Jonas depends on pictures. That is why we spent some time looking for pictures on the Internet together. We copied them into Word and Jonas added the names of each item to the pictures. Everything was nice and large and clearly arranged. When we went into the kitchen later, we took them with us and Jonas placed them next to his work surface. When I then said, “Jonas, we need a pot”, he looked at his notes, nodded briefly, and got the pot. Today we cooked semolina again but this time without a packet and following my instructions. He needed to heat some milk. We watched the milk very carefully and took it off the heat as soon as it began to boil. He added the sugar and the semolina. Everything worked perfectly today. Jonas did many things by himself and I’m relaxed again. So, of course, is he.
Day 8 – “Use both hands!”

It's just before noon and we are cooking again.

Jonas got his help-notes, put them on the worktop and got started. He doesn't really need them, but they are there and give him security. Today's menu was pasta with sauce. Following my instructions, he pulled out a pot, put the kettle on, and turned on the cooker ring. Today, we also needed a lid. A quick look at his notes and he knew what I meant. But which lid is the right size? This time, I don't help him but let him work it out. The first lid was much too small and plopped straight into the water. Luckily, it was not yet hot and he fished it out again. The next lid was much too big, another one again too small (this time he held it and did not let it fall in) until, finally, he found the right one.

He cut open the bag of pasta and learned again that if you cut too close to the top, the packet will not open. The water boiled and Jonas put the pasta into the pot. I had to tell him again-and-again to use both hands. I noticed that he persisted in using the pincer grip when stirring the pasta. I showed him how to hold the cooking spoon properly and after saying “use both hands!” 10 times, we were done and we set the table.
Day 9 – Cooking with an audience

We took three days off from our cooking project and during this time we picked up his sisters from their holiday. From now on, the house and the kitchen would be full of hustle and bustle again. Jonas was very proud and wanted to show his sisters that he can cook. They stood around him, asking question after question and giving good advice. However, it is an even greater challenge for Jonas to cook under such conditions. So first we had to clarify that everyone must be quiet when Jonas is cooking and only Jonas cooks and no-one else. There were approving nods from all sides.

This time I thought we would cook using the Thermomix but wondered if it might be too much of a change for Jonas. However, Jonas loves technology and was very keen to start. In fact, I realized he was coping just fine. The only thing he cannot do is operate the lid because he does not have the strength. Nevertheless, cooking with the Thermomix seems like it could be a good alternative for Jonas. I would only have to think about translating the recipes for him into simple language, because here too he is overwhelmed by terms such as “broccoli in small florets”. Following my instructions he heated the oven on his own. I put the casserole dish in myself and took it out again later. We had a tasty pasta and broccoli bake, which even Jonas ate. Since he has started cooking he has also become a little more courageous in tasting food and meals.
Day 10 – Chopping needs to be learnt, too

For our dinner today, we thought we would make fried mushrooms with scrambled eggs. But we don't put whole mushrooms in the pan; they first need to be chopped. However, chopping needs to be learnt, too. I don't think he can stand hearing my standard phrase “Use both hands!” anymore, but I have to keep reminding him. He only uses one hand to chop the mushrooms - this means that he’s pressing the knife more or less into the mushroom. I showed him over-and-over again how to hold the mushroom and then cut it.

The frying later on was child's play in comparison. He needed a frying pan and, after briefly glancing at his notes, he fetched one. ...turn on the heat, melt the butter, add the mushrooms and stir. The only thing he wanted to delegate was breaking the eggs.

I: “And now we still need eggs.”
Jonas: “But why?”
I: “Because it tastes very good with eggs.”
Jonas: “But you can do that.”
I: “But you're cooking.”
Jonas: “No, but it makes my hands get dirty.”
I: “But you can wash your hands again. And we want to practice cooking.”
Jonas: “So I can live alone in the house when I'm 20?”
I: “Yes, so you can live alone.”
Jonas: “Right, okay.”

We had a delicious dinner. Jonas also tried some mushrooms with eggs, which he has never done before.

On the 11th day we “only” practised cutting and produced a colourful plate of mozzarella, mini tomatoes and cucumber.
On the **12th day**, we cooked hot food again. We had potatoes and parsley sauce with sliced hard-boiled eggs. I did the potatoes because he cannot peel them. But the sauce was all his doing. Following my instructions, it worked very well.

On the **13th day**, all the children wanted to cook together. But the girls were a big distraction for Jonas. This meant that he looked at everything else except what he was doing. Today we had salmon casserole with rice. Yet again, I was forced to realise how little strength Jonas has. Opening a bottle of cream was quite impossible.

**Day 14 – et voilà**, we have managed 14 days. Despite the ups and downs, he still enjoys cooking. It has become a daily ritual for him, and he just can’t wait for his “jobs”. What did we have today? A pasta bake. For Jonas, this meant measuring liquids, cutting ham, boiling pasta and operating the oven. By the way, we were given a new measuring cup as a present; one which has just one scale in millilitres with nice big black numbers. A huge relief for Jonas.

We cooked on three further days and kept trying new things out. Sometimes with more help and sometimes with less. But Jonas has definitely understood the basic techniques and terminology.
With the new school year starting, we will not be able cook together regularly. We want to let him work with the pots and pans at least once a week, and use the holidays to consolidate his knowledge. If the intervals between the cooking sessions become too long he forgets the routine and everything he has learnt.

In summary, it was only while we were doing something together with Jonas that I realised how limiting visual and hearing impairments can be in terms of access to information and understanding of the world around us. Nothing can be taken for granted and all knowledge is hard earned.

A large part of the success of Jonas’ cookery school is due to the patient and repeated addressing and clarification of Jonas’ questions of “why?” and “what for?” For Jonas to remain motivated, everything he learns must have a purpose. In his case, his big goal of living alone at the age of 20 gives him all the motivation he needs.

My task now is to get suitable kitchen aids and to prepare more of those help-notes. Above all, however, I want to find out what other practical aids help disabled people to be able to cook. And I can imagine that Jonas might prepare a dish on his own one day, if we find a cookbook that uses simple language. Yes, and then the idea of “having the house to himself” could actually become reality.

Claudia Junghans with Jonas (CHARGE syndrome)

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